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Perceptions and psychosocial impact of food, nutrition, eating and drinking in people with inflammatory bowel disease – a qualitative investigation of food-related quality of life

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41

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44

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63 **Running head:** Psychosocial impact of food in IBD

64

65

66 **Abstract**

67 **Introduction:** Extensive research has provided an important understanding of the impact of
68 inflammatory bowel disease (IBD) on nutrient intake, requirements and metabolism. In
69 contrast there has been limited research examining the psychosocial aspects of food, eating
70 and drinking in IBD. This study aimed to address this unmet need.

71 **Methods:** Qualitative semi-structured interviews regarding the perceptions and psychosocial
72 impact of food, eating and drinking were undertaken with 28 purposively selected people
73 with IBD. Interviews were audio recorded and transcribed verbatim. Colaizzi's framework
74 was used to structure data analysis.

75 **Results:** Five major themes were identified. IBD symptoms and both surgical and medical
76 treatments were described as having a direct impact on eating and drinking, while participants
77 also used different food-related strategies to control IBD symptoms. These included a process
78 of experimenting to identify trigger foods, following a severely restricted and limited diet,
79 eating small portions and eating more frequently. However, their limited knowledge about if,
80 and how, food affected their symptoms, often resulted in negative coping strategies that
81 impacted on psychosocial functioning, including lack of enjoyment of eating, being afraid to
82 eat and finding social occasions stressful. Managing food and drinking also made food
83 shopping and preparation more burdensome, created problems with families, at work and for
84 social life as well as the need for careful preparation and advanced planning of activities.

85 **Conclusions:** IBD has a profound impact on psychosocial aspects of food and nutrition, that
86 impacts on 'food-related quality of life' (FRQoL). Further research is required to identify
87 interventions that will improve FRQoL in patients with IBD.

88 Introduction

89 The treatment of inflammatory bowel disease (IBD) concentrates primarily on
90 gastrointestinal and extra-intestinal symptom management.¹ The chronic nature of the
91 condition and the difficult-to-manage symptoms of IBD, such as diarrhoea, abdominal pain,
92 fatigue and weight loss, may affect many aspects of an individual's life and may significantly
93 impact their quality of life.^{2,3}

94 Extensive research over the past two decades has led to an improved understanding of the
95 impact of IBD on nutrient intake, requirements and metabolism.⁴⁻⁷ Whilst these aspects are
96 crucially important, there has been limited research related to the psychosocial aspects of
97 food, nutrition, eating and drinking in IBD, including social, emotional and cultural aspects,
98 despite people with IBD considering this to be an important area for research.^{8,9}

99 Apart from numerous biological roles, food fulfils a host of social and psychological needs,
100 such as being a source of pleasure, a coping mechanism, and communicating an individual's
101 belonging to particular social and cultural groups.^{10,11} These important psychosocial roles
102 may be dramatically altered in people with IBD, especially as it can affect people of all ages,
103 gender and ethnicities, for whom food may have a wide variety of roles and meanings. For
104 example, eating may be associated with symptoms, malnutrition can limit daily life and diet
105 therapy is used in disease management. Eating and drinking are also central to many social
106 interactions with family, friends and colleagues and IBD can therefore inhibit some people
107 from socialising.¹²⁻¹⁴ Indeed, one survey reported that 82% of people with IBD experienced
108 problems with food and nutrition, including issues with trigger foods and impaired social
109 activities.⁸ Despite attempts to emphasise normality and control in their lives, some people
110 with IBD experience negative psychosocial impacts associated with food, impacting on their
111 food enjoyment and self-identity.¹³

112 Despite previous research findings indicating that food, nutrition and social interactions are
113 of high importance to people with IBD⁸ and that they would like issues around diet and
114 lifestyle to be discussed during clinical consultations,¹⁵ they have limited access to dietetic
115 services¹⁶ and inadequate support and advice in relation to understanding the psychosocial
116 aspects of food in IBD.¹⁷ The existing empirical research into experiences of food and
117 nutrition in people with IBD is limited to small questionnaire surveys. The published
118 qualitative studies predominantly conflate the experiences of people with various
119 gastrointestinal disorders,¹²⁻¹⁴ although an online interview study in IBD identified numerous

challenges experienced by people with IBD in relation to food, nutrition, eating and drinking and their impact on their lives.¹⁸ Further study into the psychosocial impact that eating and drinking can have for people with IBD is warranted. The aim of this study was to explore the perceptions and psychosocial impacts of food, nutrition, eating and drinking on the lives of people with IBD.

Methods

In-depth, semi-structured qualitative interviews were conducted with people with IBD to explore the perceptions and psychosocial impacts of food, nutrition, eating and drinking. The study selection criteria were a confirmed diagnosis of either Crohn's disease (CD) or ulcerative colitis (UC), 16 years of age or over (with no upper age limit), able to eat some normal food, able to consent for themselves and an ability to speak English fluently. Participants were excluded if they were currently treated with exclusive enteral or parenteral nutrition and did not eat solid food. Additionally, being pregnant or breastfeeding, a diagnosis of an eating disorder or chronic illness (e.g. end stage renal disease) that could affect participant's ability to eat and drink normally were also exclusions.

Patients were recruited from outpatient clinics at two large London teaching hospitals. Specialist clinics for general gastroenterology and IBD clinics were targeted for recruitment. A purposive sampling strategy was used. Potential study participants were identified during scheduled outpatient appointments by a member of the clinical team.

The interviews were based on questions developed drawing on the previous literature including previous research undertaken by the study team,⁸ and focused on the issues of food and symptoms, food and social interaction with friends and family, effect of food and eating on symptoms, effects of food, eating and drinking on life and nutritional status, and adaptations to managing these issues (Table 1). For the purpose of clarity, the questions were reviewed by the research team and tested with one participant.

Insert Table 1 here

All interviews were conducted face-to-face, either in a quiet room at the university (n=5), hospital (n=8) or at the participant's home (n=10) or place of work (n=5), according to their preference. Participants were encouraged to talk openly about issues that had the most relevance to them and responses clarified and probed as necessary. All interviews were audio-recorded and transcribed verbatim by a professional transcriber. After 20 interviews

were conducted, the subsequent interviews did not identify any new issues related to the topic of the study, indicating that saturation had been achieved. Further eight participants were interviewed both to examine whether data saturation was achieved, and because the participants had already agreed to take part in the study.

Thematic analysis was undertaken based on Colaizzi's 7 step framework¹⁹ (Table 2). The NVivo 11 package for qualitative data analysis was used to manage data. To improve rigour of the study, two experienced qualitative researchers were involved in data analysis (WCD and MM).

Insert Table 2 here

The study was approved by the South West Frenchay National Research Ethics Committee (Ref: 11/DW/0291). A participant information sheet was provided to interested participants and all were given sufficient time to consider their participation. Those interested in participation provided written informed consent. Participants were reminded that the interviewer (LDH) had no direct involvement in their care. The principles of confidentiality and anonymity were applied throughout the study, by giving participants pseudonyms and deleting any data (e.g. hospital name, consultant name, geographical location) that may have led to individuals being identified.

Results

Study participants

Of 48 eligible patients who expressed an interest in participation, 28 (57.1%) were subsequently interviewed. Reasons for not interviewing included: being unable to arrange a convenient time (n=5), patients changing their minds (n=5) and non-response to follow-up contact (n=10). Twenty-eight patients with IBD were interviewed, 16 CD (9 female) and 12 UC (6 female). Participants' demographic and clinical data are presented in Table 3. The median time since diagnosis was 7 years with ten diagnosed for ≤ 4 years, eleven for 5-10 years and seven for over ≥ 11 years. The interview time ranged from 29-91 minutes depending on the detail of respondents' accounts. There were no noticeable differences of food experience between people with CD and UC, therefore, the results are presented together for these two groups.

Insert Table 3 Here

Study themes

Five themes were identified from the data, each containing several sub-themes (Table 4). For succinctness, the data are presented under the main themes only, incorporating all the sub-themes. Direct participants' quotes are presented in *italic* with participant's identifiers of pseudonym, gender, age and diagnosis.

Insert Table 4 Here

Personal experience of relationships between IBD and food

Participants made a direct link between IBD diagnoses and associated symptoms, with the impact being their perceived dietary restrictions. Equally, participants talked extensively about their perceived relationship between the food they consume and the presence or severity of the IBD symptoms.

Many participants reported loss of appetite as the main problem related to their IBD: *'My appetite is one of the first things to go during a flare. So that's the most noticeable thing. I won't feel hungry at all, I can go pretty much all day without eating anything'* [Kush, M, 18, CD]. Other symptoms, such as abdominal pain, diarrhoea, bloating, mouth ulcers and loss of taste, also affected diet, particularly when IBD symptoms were more severe: *'When your IBD is flaring and you are not well, you just don't want to eat, you just don't want any food to touch your lips'* [Tessa, F, 63, CD], but returning to normal diet when well: *'If I'm having no symptoms or flare-up, it's not bad, and I can eat absolutely anything'* [Amanda, F, 35, UC]. There were some participants who made no change to their diet as a result of their IBD diagnosis: *'There's nothing in my UC that makes me eat differently ... I don't schedule my eating in any form at all to do with UC'* [Andrew, M, 44, UC], and others that constantly tried to judge the interaction between their IBD symptoms and making decisions regarding what to eat: *'It feels like my body is telling me what's not good for me'* [Beth, F, 35, CD].

Factors related to medical and surgical treatments affected participants' decisions about whether and what to eat. For example, the increased appetite during steroid treatment was often a period of when participants felt unrestricted about their diet, despite the greater severity of their IBD symptoms: *'If I'm on steroids that definitely affects what I eat. So I eat more. But for me at that time it's usually a good thing because I've usually lost a lot of weight'* [Paul, M, 25, CD]. However, some were also concerned about the negative effects of overeating on excessive weight gain as a result of steroids. IBD-related surgery (e.g. stoma,

212 ileo-anal pouch- anastomosis), surgery-related complications or intestinal strictures were
 213 reported by participants as impacting on their food consumption: *'Since surgery, foods are*
 214 *trial and error... I do have bouts of pouchitis and bleeding and stuff occasionally. So that*
 215 *took a bit of getting used to, because I could just eat anything before the bowel was removed*
 216 *and then realising afterwards that certain foods like salad and fruit, I can eat them now, but I*
 217 *wasn't retaining anything. It would just come out solid'* [Stephan, M, 42, UC].

218 Participants talked about altering their diet as a direct effect of IBD: *'Before [IBD], I never*
 219 *thought about not eating certain types of food, just when [since] I had the colitis'* [Stephan,
 220 M, 42, UC]. The perceived close link between IBD symptoms, frequency of going to the
 221 toilet and food, created negative emotions: *'I think because you're going to the toilet all the*
 222 *time you're not holding down food, then you get scared to eat ... It got to the point where I*
 223 *was nervous and you get that nervous tummy and I was going to the toilet a lot, then I'd just*
 224 *stop eating'* [Ellen, F, 32, CD].

225 Food was not seen as a direct reason for causing a flare, but it was linked with symptom
 226 deterioration during active disease: *'No, I don't think what I eat actually contributes to the*
 227 *flare-up, I don't think it causes it, but I think when I'm having a flare-up, what I eat can*
 228 *certainly exacerbate the flare-up'* [Esther, F, 38, UC]. Participants talked about certain foods,
 229 or a group of foods, as a trigger exacerbating their IBD symptoms. The specific trigger foods
 230 varied widely between individuals including spicy foods, high fat foods, red meat, dairy
 231 products, fruit, vegetables, alcohol, coffee and fizzy drinks, and the symptoms exacerbated by
 232 food consumption included pain, diarrhoea, bloating, frequency and urgency, nausea and
 233 vomiting, and a feeling of heaviness and fatigue. Some participants linked these symptoms
 234 with a particular food: *'I've noticed that sometimes there are certain things that I eat will*
 235 *aggravate, like spicy foods ... After I've eaten something spicy, the next morning I'm just on*
 236 *the toilet a lot'* [Anna, F, 17, CD], while others perceived eating in general as triggering their
 237 symptoms: *'Nothing really affected it [symptoms] that I could pinpoint then because it was*
 238 *literally everything, everything that went past my mouth ... even a sip of water ... or a bite of*
 239 *biscuit would send me running to the toilet'* [Catherine, F, 37, UC]. Some participants linked
 240 symptoms to the portion size (larger portion) or the frequency of eating (irregular meals).
 241 However, there were also some participants who did not specifically link food or eating with
 242 IBD symptoms: *'I mean if you'd eaten a load and then you had to go [defecate] quickly ...I*
 243 *think that's more like a general symptom anyway'* [Martha, F, 29, UC].

244 **Managing diet to control IBD and its symptoms**

245 Whist participants' reported food and eating exacerbated their IBD symptoms, they
 246 commonly tried to unravel this relationship and used diet to manage their symptoms: *'There*
 247 *was clearly something wrong and the obvious cause for this was something that I eat. So*
 248 *what can I do other than removing certain things to see if it has an effect, adding certain*
 249 *things to see if it has an effect'* [Andrew, M, 44, UC]. The methods most frequently used
 250 were food restrictions, food exclusion, food substitution, changing food preparation, all of
 251 which required constant planning. All participants talked about experimenting with food by
 252 excluding 'bad foods' and replacing it with 'good foods'. However, the list of bad foods and
 253 good foods differed between participants and was influenced by perceived food intolerance or
 254 the exacerbating IBD symptoms.

255 Opinions regarding healthy eating were widely polarised, with some trying to follow the
 256 advice of health professionals to increase intake of fruit, vegetables, fibre and having a
 257 balanced diet, while others were questioning the meaning of healthy diet in IBD: *'Knowing*
 258 *what a healthy diet is and realising that's not going to be particularly healthy at that point in*
 259 *time for me from a colitis point of view'* [Adam, M 41, UC]. Intake of fibre was increased by
 260 some, while some did the opposite: *'The only change I have made now is that I don't eat a lot*
 261 *of fibre. I used to have wholemeal bread, brown rice, brown pasta etc., but now I have white*
 262 *instead because I know that having a lot of fibre makes you go to the toilet more'* [Catherine,
 263 F, 37, UC]. For participants who had vitamin and mineral deficiencies or were underweight, a
 264 healthy diet was interpreted as one that helped them to gain weight: *'I was massively*
 265 *underweight, and I did see a dietitian for a little bit, but we didn't look at what kind of foods*
 266 *were making me worse or better ... I was just eating everything and anything, it's just that*
 267 *I've been trying to put weight on'* [Thomas, M, 25, CD].

268 All participants talked about experimenting with food by either following an exclusion diet
 269 and then slowly re-introducing the excluded products, cooking very plain food, mashing or
 270 liquidising food, which they perceived made it easier to digest. Often participants did not
 271 follow the changes for any specified period of time or did not keep a food/symptom diary to
 272 record how effective the changes were. In most cases this was not done under the supervision
 273 of a healthcare professional but was down to participants' own experimentation. There were
 274 some participants who followed a severely restricted and limited diet in the belief that there
 275 will be fewer foods to exacerbate symptoms. In others, food choice was based on their likes

and dislikes, as they preferred to have enjoyment of food and if necessary to deal with consequences of having to go to the toilet more frequently. Many participants talked about knowing or anticipating unpleasant outcomes (e.g. abdominal pain, increased stool frequency), but persevered with eating particular food(s) because they had denied themselves this pleasure for so long.

Eating frequent and regular meals, eating slowly and small to moderate portion size were all used as possible methods to limit the negative impact of food on IBD symptoms: *'I'm trying to eat four or five times a day – smaller amount. It's better for me'* [Beth, F, 35, CD], while some try to avoid eating altogether: *'If my stomach's playing up, so normally I would starve my stomach so that there's nothing in it. Sometimes I don't eat the whole day'* [Ellen, F, 32, CD].

Impact of food-related issues on everyday life

The food-related issues described (personal experience of IBD and food, managing diet to control IBD and symptoms) impacted patients' everyday life. For participants to be able to 'get on' with their life, they had to plan many activities in advance, from going food shopping, food preparation, through to work, hobbies and socialising.

Due to actual or perceived food restrictions related to IBD, food shopping (e.g. checking ingredient labels) and food preparation was more time consuming: *'I'd look on the labels to make sure I didn't think it would upset me'* [Jalal, M, 51, CD]. Participants perceived food preparation to be more burdensome: *'It's the cooking that sometimes really upsets me because I have to cook twice'* [Mary, F, 56, CD], while others used more flexible methods such as separating food for themselves before spices or certain ingredients were added for family members (e.g. onion, garlic).

Depending on how restrictive or varied the type of food and the recipes were, participants found differing levels of support from their partners and family members, with some being more willing to compromise, while for others mealtimes resulted in conflict or not eating together: *'Everybody else in the house was continuing with their normal diets and I would usually end up eating separately'* [Kush, M, 18, UC]. One participant felt that she had to be a positive role model and give a good example to her daughter: *'it's not just myself that I'm eating, you know planning meals for. It's also making sure that my child has a healthy concept of food and a healthy relationship with food'* [Ester, F, 38, UC].

307 Some participants reported food-related issues and the effect on their symptoms as impacting
 308 on their daily functioning. Needing to visit a toilet soon after eating created anxiety for some:
 309 *'I'm a bit scared to eat because I know I'm going to need to run to the toilet'* [Beth, F, 35,
 310 CD]. The work environment created very specific challenges to people with IBD. Some tried
 311 to be organised and plan ahead and to take their lunch to work to give themselves as much
 312 control as possible: *'It's nice to know that there are things that I can eat, that are there*
 313 *available to me when I want it'* [Dahlia, F, 22, CD]. While others would eat less or avoid
 314 eating all together: *'A big part of it is my eating habits, because when I'm at work I don't eat,*
 315 *because I know if I eat I have to go to the loo ... If I knew I had to be out all day, I probably*
 316 *would consciously eat less the day before'* [Thomas, M, 25, CD]. Where possible, some
 317 participants tried to work from home, as this way they felt unrestricted about the frequency of
 318 eating while also being close to the toilet. Other strategies to manage IBD symptoms also
 319 created problems for some in the work environment (e.g. more frequent meal breaks,
 320 avoiding specific foods), due to a lack of understanding among their colleagues: *'I feel like*
 321 *they are looking and, 'Oh she's eating again,' you know. I think they don't understand. They*
 322 *know that I have this disease but they don't know how it affects me'* [Beth, F, 35, CD]. Some
 323 female participants reported feeling faced with suspicion if they were not drinking alcohol at
 324 work events: *'If you're a woman and you're not drinking, people start making assumptions,*
 325 *'Oh is she pregnant and is it going to impact on her career?'* [Janet, F, 29, UC].

326 Social lives were greatly impacted, and in a wide variety of ways, by having IBD and food
 327 restrictions. For some, symptoms associated with eating, particularly higher frequency of
 328 visiting the toilet, needing a toilet during a meal and pain after eating, were strong deterrents
 329 from going out and socialising: *'It's awkward when, if you're at a restaurant and all of a*
 330 *sudden you have to bolt to wherever the toilet might possibly be'* [Gary, M, 30, CD]. Many of
 331 the study participants felt nervous about eating out in new places, as they were apprehensive
 332 about unfamiliar menus and certain food ingredients that they may be intolerant of: *'Before I*
 333 *go, I really study the menu and see what to have'* [Mary, F, 56, CD]. For some, going out to
 334 eat was part of carefully planned exercise rather than a spur of the moment decision: *'Me and*
 335 *my husband both work. We could go out whenever we want, but we end up at the same few*
 336 *restaurants and I know exactly what I'm going to take before I even walk through the door'*
 337 [Sandra, F, 41, CD]. This reduced the pleasure of going out for some people. Some
 338 participants would choose to socialise but would not eat when doing so: *'Even if I couldn't*
 339 *eat I was going out anyway just to socialise with my friends'* [Dahlia, F, 22, CD], while

340 others would refuse ‘dinner dates’ and find an excuse not to go (e.g. infection, food allergy),
 341 so as not to disclose their IBD diagnosis. Special occasions such as birthdays, weddings or
 342 festive holidays were perceived by some as difficult and stressful to deal with, while others
 343 took more relaxed approach and were prepared to experience the symptoms that celebratory
 344 eating would cause. Those who had more experience of living with IBD felt better able to
 345 cope with different situations: *‘If a friend is going to take offence because I don’t eat the full*
 346 *portion, then that’s their problem’* [Katy, F, 47, CD].

347 Some, who were unable to drink alcohol, felt reluctant to go out to social events where
 348 alcohol was involved, as they thought that that they would ruin enjoyment of others, or feel
 349 pressure from others to conform: *‘I went to my friend’s birthday when I was very much off*
 350 *alcohol and, they were saying ‘Oh go on, have a glass of wine.’ I know that it was much more*
 351 *important for me not to’* [Janet, F, 29, UC], while some were resilient to the social pressure of
 352 drinking: *‘Alcohol doesn’t rule my life. I could have it or I could do without. And I prefer to*
 353 *do without it ... If I actually go into a pub, with my wife or with a couple of friends, they have*
 354 *alcohol and I have orange juice’* [Robert, M, 59, UC].

355 **Acceptance and normalisation of food and its impact in IBD**

356 Many participants talked about negative emotions linked with the psychosocial impacts of
 357 food, nutrition, eating and drinking with IBD, including stress, annoyance, frustration and
 358 low mood.

359 Acceptance of IBD diagnosis and changes to everyday life featured strongly in participants’
 360 experience of food, nutrition, eating and drinking with IBD. This was closely linked with
 361 participants trying to normalise their life. For some, normalisation was expressed by eating
 362 ‘normal food’ and trying to live their life as before their diagnosis, trying to ignore their IBD
 363 diagnosis and trying to cope with a higher frequency of going to the toilet: *‘I don’t really like*
 364 *being labelled with it [colitis]. I sort of don’t like the pity. I just want to be able to get on with*
 365 *my life and with my job. Not let it interfere in my life, insofar as that is possible’* [John, M,
 366 35, UC]. Some tried to achieve normalisation by controlling their diet, being careful what
 367 they eat, in hope that this would help them to control the symptoms: *‘Eating healthier and*
 368 *cutting certain things out hasn’t all been bad. Most of it has been good and it makes me feel*
 369 *good knowing that what I’m eating is also good for me and good for my colitis’* [Kush, M,
 370 18, UC].

Having control was frequently mentioned and being in control was important for participants. Accepting their condition was seen as a first step to controlling it. However, when participants felt unable to control their disease, they sometimes tried to control their diet: *'By making many adjustments to food and drink and general lifestyle as I reasonably can without going completely over the top. That how my life is'* [Katy, F, 47, CD]. Other forms of control were learning more about what food to eat and what food to avoid, being aware of the environment and where the toilets are, getting to know their body and how it responds to different foods. Hence, participants' life was based around their IBD and constant thinking about food, its nutritional value and whether or not it will induce symptoms: *'I plan everything around my body rather than planning my life then making my body work around it'* [Thomas, M, 25, CD]. Some participants were prepared to make and accept these changes without *'being morbid and dwelling on things'* [Esther, F 38, UC], while some missed the pleasure of being unrestricted about food and food choices: *'I miss having normal diet, I always liked my food and I miss just having what I want'* [Catherine, F, 37, UC]. They tried to be strong, but they did not manage to succeed all the time, particularly as the restrictions and sacrifices did not always work: *'It does vary on a day to day and that's probably the hardest part, because there are times, there are certain things that are going to cause a reaction'* [Gary, M, 30, CD]. This constant uncertainty only led to more frustration, irritation and doubts in the strategies used.

Sources of information and support

Many participants expressed their limited knowledge and understanding of CD or UC and how diet may affect their condition: *'I don't know enough about whether there are differences between normal healthy eating and eating to help colitis'* [Janet, F, 29, UC]. Hence, they sought help and support about diet in IBD from health professionals. Many participants received diet advice at the time of IBD diagnosis from a gastroenterologist, but the advice frequently consisted mainly of: *'It doesn't matter what you eat'* [Tessa, F, 63, CD] as diet is not linked with IBD. Some were more accepting of that advice to continue with their normal diet, while others were finding it difficult to accept: *'I cannot see how a digestive illness can't have links to food because it just doesn't make sense to me'* [Agnes, F, 31, CD].

Most participants were not offered special dietary advice, but were told that they could eat everything, while others, depending on the presenting symptoms and their severity (e.g.

severe abdominal pain or severe weight loss), were referred to a dietitian for advice on an elimination diet, enteral nutrition in CD, low fibre diet or high energy diet. Participants' experience of advice given by dietitians also differed. Some were told to eat '*all things in moderation*' [Jason, M, 56, CD], some to restrict their diet at the time of flare, while others were told to eat everything and during flare to increase their energy intake. As a result, satisfaction with dietitians' advice and support varied, with some finding it very helpful: '*I was in close contact with her (dietitian) and if anything happened, I would just email her*' [Dahlia, F, 22, CD], and some finding the advice generic and non-specific: '*It wasn't as helpful as I thought it would be. It's sort of pretty obvious what she said to me really, to stay clear of fibrous food*' [Jalal, M, 51, CD]. However, some unsuccessfully tried for many years to be referred to a dietitian, and some were of an opinion that if: '*My medical doctor told me there's no known correlation, so what would a dietitian tell me?*' [Andrew, M, 44, UC]. However, many participants did not know what food they should eat or what food to avoid, and if they needed vitamin and mineral supplements.

Only a few participants mentioned dietary support and advice given by IBD specialist nurses. Most of the advice concentrated around principles of healthy eating (e.g. five portions of fruit and vegetable per day).

Some participants thought that health professionals did not take food issues in IBD seriously, or that clinicians were too busy to talk to about diet. Some found the advice superficial, confusing or even conflicting. Hence, participants tried to find diet-related advice by accessing other sources of information, such as seeing dietitians privately, internet IBD forums and discussion groups. Their satisfaction with information obtained from these sources also varied. Some found the information useful, some thought that they have to find their own way of coping, while some talked about an increased anxiety about food and food restrictions and developed very restrictive dietary habits.

Participants, who disclosed their IBD diagnosis to others, found their friends and family to be supportive and understanding. Some of the help and support was more practical (e.g. advice on what to eat or what food to avoid, cooking food that met the individual's preferences) and some was in the form of emotional support: '*They don't really say nothing about my weight [being underweight] and that makes me happy because I'm really self-conscious about my weight*' [Anna, F, 17, CD]. Many participants expressed a wish for a greater support from family and friends, however their IBD and food-related knowledge was often limited: '*My*

friends know I have Crohn's, but probably a lot of them have never heard about it, so they don't really understand what it is and how it affects me' [Beth, F 35, CD], hence, their advice was not always relevant: 'It gets really frustrating when people get confused between irritable bowel and inflammatory bowel, suggesting I go dairy free... or to do this or do that... I'm there thinking well it doesn't make any difference' [Adam, M, 41, UC].

Discussion

This qualitative study explores the experience and psychosocial impact of food, nutrition, eating and drinking on the lives of people with IBD. Participants reported close links between IBD and food, in that IBD affected their ability to eat some foods due to its impact on symptoms, while diet was also used as an approach to manage these symptoms. This bi-directional relationship in most cases had far reaching, negative and compound impacts, requiring restrictions and sacrifices in their private, social and professional lives. Patient-reported experience of food-related issues in IBD restricting their quality of life, are supported by survey data suggesting 82% of people with IBD experience such problems with food and nutrition.²⁰

Active disease and the severity of symptoms such as diarrhoea, urgency, abdominal pain, bloating, nausea, vomiting, loss of appetite and mouth ulcers were presented as the main factors affecting participants' food choice. Participants restricted the range of foods consumed, completely excluded some foods, reduced the amount or frequency of eating, or all of these, in attempts to adapt their life to their IBD. These behaviours may contribute to nutritional problems frequently reported in IBD including micronutrient deficiencies, malnutrition and even overweight. Between 20-85% of people with IBD have been reported as being at risk of malnutrition.^{21,22} Malnutrition is associated with suboptimal health outcomes,²³ reduced quality of life,⁴ fatigue,²⁴ and diminished strength.²⁵

Even during IBD remission, participants observed that certain symptoms e.g. abdominal pain, diarrhoea, bloating, frequency and urgency, nausea and vomiting, heaviness and fatigue, were exacerbated by eating in general, or by certain food groups, or by spicy or fatty food. At the same time the presence of these physical symptoms affected participants' appetite and made them anxious about eating. It could be argued that presence of gastrointestinal symptoms during remission may indicate presence of functional, rather than inflammatory symptoms.^{12,26} However, the aim of the current study was to explore the perceptions and psychosocial impacts of food, nutrition, eating and drinking on the lives of people with IBD,

and this was irrespective of whether the experiences resulted from symptoms that were the result of active disease, functional gut symptoms, both or neither. Interestingly, a previous qualitative study investigated the experiences of eating among eight women with either IBS (i.e. functional symptoms alone) or IBD. Although few comparisons were made between the two conditions, similar experiences were identified to those reported here (healthy eating, trigger foods, dietary restrictions, control, support from family and friends).¹²⁻¹⁴

There are wide ranges of prevalence of functional gut symptoms reported in IBD, mainly due to heterogeneity and challenges of defining them,²⁶ however pooled prevalence of those satisfying definitions of IBS in IBD was 39% (44% in active, 35% in remission).²⁷ This suggests that over one third of IBD patients could be considered for optimising functional gut symptom management, which may include modification of diet, lifestyle, psychological and pharmacological treatments.²⁸ Dietary approaches to managing functional gut symptoms in IBD include the low FODMAP diet which has some evidence from both uncontrolled²⁰ and controlled studies.²⁹⁻³¹ The term FODMAP is an acronym for Fermentable Oligo-, Di-, Monosaccharides And Polyols, short chain carbohydrates that are poorly absorbed in the small intestine.³² Although improved research on the efficacy of the low FODMAP diet is required, patients in the current study frequently reported foods high in fructans (e.g. onions, garlic) to be associated with abdominal pain, bloating and diarrhoea and this has been confirmed in re-challenge studies in IBD.³⁰ If patients' complaints of functional gut symptoms reported during remission are not listened to, nor formally evaluated by clinicians, this may lead to a lack of trust between patient and clinician, and lead patients to seek information elsewhere and/or develop adverse behaviours with restrictive diet habits, that may be nutritionally inadequate.^{13,20,33,34,35}

Participants did not link their IBD diagnosis or any relapses to their diet. However, they were strongly of the opinion that they could use diet as a means to manage their symptoms. Similar views are found in the literature, where diet is reported to influence intestinal inflammation (e.g. altering the gut microbiome), however with scarce evidence that diet alters the natural history of IBD.^{7,36-39,40,41} Food restrictions and exclusions, and experimenting with food by trial and error were reported by participants as methods frequently used to control their IBD symptoms. Participants found these methods practically challenging in terms of shopping, cooking, finding recipes, and this caused many emotional challenges in terms of them being able to socialise, take part in special occasions, and to enjoy food in the same way as before the IBD diagnosis. Similar issues have been reported in previous studies.^{35,40}

Participants talked about having to plan in advance their daily activities, constantly having to think about what and where to eat, and access to toilets. This constant planning and restriction created stress and anxiety, and contributed to diminished enjoyment of food and everyday life. Many participants felt that they had lost control of their lives and that they were leading more restrictive and limited lives. Consumption of food and alcohol is at the centre of many peoples' social life and consumption of certain types of food is often culturally driven. Making changes to the type of food consumed or avoiding certain foods and alcohol may contribute to changes in the individual's emotions and their enjoyment of food.^{37,42} Patients decisions regarding food choice may vary depending upon their primary aim (e.g. symptom control, social engagement, participation in cultural celebrations, food enjoyment), and therefore requires constant planning, creating at times, internal or external conflicts. Diet and diet manipulation, such as food avoidance, food restriction and food substitution, were perceived by participants as a way of controlling their everyday life. Being in control of their body, IBD symptoms and their life at large was the ultimate goal, which participants tried to achieve on a daily basis.

Access to information on IBD and diet was seen as an important avenue to equip them with knowledge and achieve better control. However, lack of reliable sources, good quality information and limited guidance and support from health professionals left participants struggling to find effective management strategies.^{14,43,44} Most of the management strategies reported by participants related to making restrictions to their diet (identifying trigger foods by trial and error, food restrictions or avoidance and its reintroduction) or their private, social and professional lives; or both. Some of the strategies were positive (e.g. following healthy and balanced diet, avoiding certain foods during a flare, but returning to normal diet during remission, taking part in social life), but many were negative, with extensive food exclusions over a prolonged period of time, leading to frustration, irritation and lack of enjoyment of food.

It is unclear which factors may play a role in developing positive or negative coping strategies.^{18,41,45} Exploring the factors and having a better understanding of the adaptation process would help to provide the guidance and support required to help people with IBD overcome their physical and emotional food-related problems. Greater emphasis should be placed on assessing and addressing food-related quality of life in IBD to identify the extent and severity of the problem, the impact on patients' diet and nutrition and the wider impact on their life. A food-related quality of life questionnaire has been specifically developed and

validated in IBD.⁴⁶ This questionnaire should help to reflect the impact of IBD on individual's food-related quality of life, instigate giving help and advice specific to an individual's needs and may help to facilitate the process of acceptance and positive adaptation.

Whilst there is a wealth of evidence of specific diets being used in different patients groups, such as nutritional deficiencies, malnutrition and strictures;^{6,33,47-50} sources of information for patients helping them to maintain their healthy and balanced diet during remission are limited.^{43,51,52,53} Participants in our study were frequently advised by health professionals that there is no evident link between IBD and diet. This perhaps relates to the limited evidence for the role of specific foods in the pathogenesis of IBD onset^{48,49} and the lack of effectiveness of diet in the management in UC.^{47,54} However, there is a disconnect between health professionals' advice regarding the lack of effect of diet in IBD and patients' everyday experiences of eating and drinking with IBD. This contradictory dynamic between advice from health professionals and an individual's own beliefs about the role of diet in IBD, may leave patients feeling that their food-related concerns are ignored by their clinicians. Although participants indicated that the advice from health professionals was often provided by dietitians, the whole multidisciplinary team, including gastroenterologists and IBD specialist nurses, should understand the impact of IBD on eating and drinking to advise and support patients.

Strengths and limitations of the study

The qualitative design of the study 'gave voice' to people diagnosed with IBD and allowed for an in-depth exploration of their experience of how IBD is affecting their perceptions and psychosocial impact of food in their lives. The benefit of using semi-structured interviews is that it sets the boundaries of the topic and the direction of the conversation, compared to an unstructured approach. The limitations of qualitative research are that it involves a small number of participants and the findings relate predominantly to these individuals. Although the main aim of qualitative research is to provide an in-depth description of the study participants experience, it is nevertheless, expected that the findings will be transferable to similar contexts which in this case comprises participants with similar clinical and demographic characteristics.⁵⁵ Greater effort needs to be directed towards recruiting participants from more diverse ethnic and cultural backgrounds. Use of semi-structured interviews may restrict the participants to primarily cover the topic set out by the interview

guide, instead of covering all of the aspects related to their experience. This limitation was partly off-set by a conversational style and ‘unrestricted’ interview time, allowing the participants to express their experience and issues of importance to them more fully.

Conclusion

Food-related quality of life in IBD patients was reported to be negatively affected across a variety of psychosocial aspects of life, however the scale of the problem needs further exploration. A variety of approaches altering diet were used in an attempt to find an optimal way to function. However, insufficient information or lack of support from health professionals resulted in many participants’ feeling trapped in using trial and error cycle as a preliminary coping strategy. Patients with IBD need diet and life style advice that will help them to make positive adjustments. Currently, there is insufficient evidence on what that advice should be, hence further research is recommended to explore exact patients’ needs.

Transparency Declaration

The lead author affirms that this manuscript is an honest, accurate, and transparent account of the study being reported. The reporting of this work is compliant with COREQ guidelines. The lead author affirms that no important aspects of the study have been omitted and that there were no discrepancies from the study as planned and the study was approved by the South West Frenchay National Research Ethics Committee (Ref: 11/DW/0291).

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734

735 **Table 1**

736 **Topic guide for semi-structured interviews relating to food, nutrition, eating and**
 737 **drinking in IBD**

Stage of the interview process and content of the interview	Examples of probes used during the interview
Introduction and opening questions:	
Length of time since diagnosis	Could you describe when you were diagnosed with inflammatory bowel disease and how your symptoms are?
IBD symptoms and impact on diet	<p>Can you tell me if having IBD and the symptoms have affected the way you eat and drink? How do you feel about that?</p> <p>Since being diagnosed with IBD, have you made changes to your diet?</p>
Follow-up questions to progress the interview:	
Symptoms and trigger foods	Have you found any foods or drinks trigger your IBD symptoms?
Eating habits and any modifications to eating and drinking	<p>Do you think your diet affects your IBD, and if so how?</p> <p>What other factors affect your diet (e.g. cultural, likes/dislikes, trying new foods)?</p> <p>Have these been affected by being diagnosed with IBD?</p> <p>Do you avoid particular foods or drinks? What are the reasons for avoiding them?</p> <p>Do you follow a special diet?</p>
Food, family and socialising	<p>Has having IBD affected your social life and going out to eat with family and friends?</p> <p>How does your eating and drinking affect your daily life?</p>
Dietary advice	<p>Since being diagnosed with IBD, do you have problems controlling your weight?</p> <p>Have you been given any diet specific advice? What resources do you use to find the diet specific information?</p>
Reflective and clarifying questions:	

<p>Reflective questioning</p> <p>Seeking clarification</p> <p>Asking for more information</p>	<p>You said that you had to “avoid certain foods”. What foods did you avoid and why? How did this make you feel?</p> <p>You talked about (E.g. having to change your diet, not being able to socialise in relation to food) how did that make you feel?</p> <p>What did you do in that situation?</p> <p>Can you tell me more about what you did at that time?</p>
Interview closure	<p>Is there anything else that you would like to add or talk about in relation to food, nutrition, eating and drinking?</p>

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740 **Table 2**741 **Process of data analysis using Colaizzi's framework**

Steps of data analysis	Activities involved
Step 1	All transcripts were read by one researcher (WCD) to acquire familiarity with the data and to gain a broad understanding of the issues covered. The transcripts were anonymised and pseudonyms given to study participants. All other names of individuals or institutions mentioned during the interview were replaced by a professional or personal relationship status (e.g. 'gastroenterologist', 'IBD nurse', 'hospital', 'wife', 'boyfriend', etc.)
Step 2	Using an inductive process, significant words and statements relating to the topic of the study were identified from the first six transcripts and a list of codes created independently by two researchers (WCD and MM).
Step 3	The two researchers (WCD, MM) met to discuss and formulate the meaning for the identified codes and statements. Any differences were explored and were resolved by discussion and review of the transcripts.
Step 4	According to their meaning, the list of codes and statements was preliminarily ordered into themes and the consensus was reached by discussion (WCD/MM). The list of themes was further discussed with a third researcher (KW), who also read six randomly selected transcripts, to clarify the meaning and to identify any overlap. Any overlapping or repetitious codes were combined. These resulted in creation of five emerging themes and several sub-themes. The newly created structure was used to code all 28 transcripts using the NVivo 11 software by the same researcher (WCD). There was no need to create new main themes.
Step 5	Two researchers (WCD, MM) met to discuss the themes and the data allocated to each of the themes and sub-themes. The coded data were re-read to verify the meaning and the theme allocation. At this point all transcripts were re-read to double check that all collected data was

	reflected in the themes created. This resulted in some of the smaller sub-themes being amalgamated.
Step 6	<p>All of the resulting ideas were integrated into a detailed description of the identified issues. Due to word limits data were presented under the main themes only, utilising the range of direct quotes from participants' interviews.</p> <p>All the team members read the data summary and provided comments on the draft of the results.</p> <p>Further data reduction and /or clarification, retaining the original data meaning, resulted in re-drafting of the paper.</p>
Step 7	All the study researchers read and commented on the final draft.

743 **Table 3**

744 **Demographic and clinical data of the 28 study participants with inflammatory bowel**
 745 **disease**

	Crohn's disease n = 16	Ulcerative colitis n = 12
Sex, n (%)		
Male	7 (44.7)	6 (50)
Female	9 (56.3)	6 (50)
Age, y, mean, (SD)	37.6 (10.9)	37.3 (12.5)
Duration of diagnosis, y, mean (SD)	10.3 (10.9)	10.4 (10.8)
Active disease (self-report), n (%)	9 (56.3)	4 (25)
Previous IBD surgery, n (%)	7 (43.8)	1 (8.3)
BMI, mean (SD)	23.3 (5.9)	23.2 (5.7)
MUST category, n (%)		
Low risk	10 (63.6)	6 (50)
Medium risk	3 (18.2)	5 (41.7)
High risk	3 (18.2)	1 (8.3)

746 MUST– Malnutrition Universal Screening Tool

747 **Table 4 Themes and sub-themes from semi-structured interviews with 28 people with**
 748 **inflammatory bowel disease relating to food, nutrition, eating and drinking in IBD**

Theme 1: Personal experience of relationship between IBD and food	
	IBD symptoms and impact on food intake
	Impact of food intake on IBD symptoms
Theme 2: Managing diet to control IBD and its symptoms	
	‘Experimenting’ with food intake to manage symptoms
	Food avoidance, food exclusion and food substitution
	‘Bad’ food and ‘good’ food
	Frequency of eating, portion sizes and planning ahead
	Healthy eating, vitamins and minerals
	Eating preferred food and dealing with the consequences
Theme 3: Impact of food-related issues on everyday life	
	Being organised, shopping, recipes and food preparation
	Impact on family, personal and professional life
	Social occasions and eating out
Theme 4: Acceptance and normalisation of food and its impact in IBD	
	Accepting new situation and ‘normalisation’
	Being in control
	Missing the pleasure of being unrestricted about eating and drinking
Theme 5: Sources of information and support	
	Not knowing enough
	Conflicting information regarding food in IBD
	Health professionals, family and friends as sources of information and support
	Limited sources of information and support